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ABSTRACT

The paper presents an outline of an international research and demonstration project designed to evolve a paradigm for community services for severely retarded adolescents and adults in the State of West Bengal, India. It is explained that the program's special feature is to provide a community setting in all spheres of activities, so that the problem of institutionalization which is plaguing some of the advanced countries may not arise in India. (Author/SBH)

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HABILITATION PROGRAMMING FOR SEVERELY RETARDED ADOLESCENTS AND ADULTS: AN EXPERIMENT IN NORMALIZATION

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Abstract

This paper presents an outline of an international research and demonstration project in rehabilitation proposed to be conducted in the State of West Bengal in India. The project is designed to evolve a paradigm for community services for severely retarded adolescents and adults. Its special feature is to provide a community setting in all spheres of activities, so that the problem of institutionalization which is plaguing some of the advanced countries may not arise in India. In other words, a service system which may be used as an alternative to institutionalization is proposed to be developed.

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Principles and concepts of deinstitutionalization and normalization, advocated in recent years in the advanced countries, point to the need of developing alternative community methods of care and training so that the mentally retarded individual may adjust to normal community living. The key point in deinstitutionalization is to return to the community all residents who have been prepared through programs of habilitation and training to function adequately in appropriate local settings (President's Committee on Mental Retardation, 1974). Normalization principle connotes that the patterns and conditions of everyday life which were as close as possible to the norms and patterns of the mainstream of society should be made available to mentally retarded and other handicapped persons. The goal is to develop in the handicapped individuals the concepts and behaviors appropriate to the culture in which they lived (Wolfensberger, 1972). The rehabilitation project at Chandannagar is designed to field-test the above concepts, and to evolve a paradigm for community services for severely retarded adolescents and adults. The special feature of the project is to provide a community setting in all spheres of activities, so that the problem of institutionalization which is plaguing some of the advanced countries may not arise in India. In other words, a service system which may be used as an alternative to institutionalization is proposed to be developed. The contemplated model program is likely to be replicated in other parts of India, and may even be emulated in advanced countries.

The Prabartak Samgha complex at Chandannagar comprises manifold educational, cultural, business, and humanitarian institutions. It provides a full-fledged community setting. Vidyarthi Bhawan, an educational institution for children and adults, has been especially selected to host the rehabilitation project, so that the new program may be integrated into the entire school program. The senior

grade students will be encouraged, and may even be required to participate in the rehabilitation program as teacher aides and group leaders in various activities. The residents of the destitute home for women will be trained as paraprofessionals to serve in different capacities, such as ward staff, home makers, recreation therapists, and escorts. They may also provide companionship, and social supervision to some of the retarded trainees. Arts and crafts, weaving and spinning, and other cottage industries units located on the campus may also provide opportunities for the training of those retarded individuals who have the necessary vocational potential. With all these amenities, Vidyarthi Bhawan presents a unique training base for the project subjects.

Objectives

The broad object is to design individualized treatment and training plans to enable each retarded subject in the project study to come closer to the goal of self-sufficiency and self-support, based on normalization principles. This program on the planning and providing of comprehensive habilitation services to severely retarded adolescents and adults is intended to serve as a prototype of "implementive change agentry."

The specific objectives of the project are briefly described below.

1) Very little work has been done in India to establish the prevalence of mental retardation, even at the "severe" (actually moderate, severe, and profound) level. These individuals are obviously retarded, and usually obviously handicapped as well. Since prevalence determines the need for services, an epidemiological survey is to be conducted initially to estimate the prevalence rate of severe retardation in the geographic area under study.

2) Diagnosis of severe retardation can be confirmed medically (through detection of physical signs associated with mental retardation), psychometrically, and through deficits in adaptive behavior. Although medical facilities are available in India for such diagnosis, standardized instruments, especially in Bengali version, for assessment of intellectual ability and adaptive behavior are non-existent. Development of such instruments, even though they may not be much refined at the initial stage, is imperative.

3) The community services to be provided in this rehabilitation project will include a day training program and residential services, both vocationally oriented. These two components will make up an integrated program, which will follow a developmental model based on the principle of normalization. Behavior modification technique, and group milieu approach will be especially utilized in the training process. An activity center and a sheltered workshop will constitute an integral part of the program. Certain related programs, such as parent education program, volunteerism or volunteer program, and advocacy program, will be introduced and experimented with in the total community service plan.

4) The mechanisms of program evaluation will include a built-in evaluation model in the behavior management approach, and consumer evaluation.

Methodology

This long-term rehabilitation project may be divided into two broad categories for operational purposes: research and demonstration. The "research" component will concentrate on two areas: (1) an epidemiological study on the prevalence estimate of severe mental retardation, and (2) development of instruments for measuring intelligence and adaptive behavior. The "demonstration" aspect will focus on programming for habilitation of severely retarded adolescents and adults, based on the principle of normalization. These inter-related studies will be conducted in sequential phases.

Epidemiological Survey

Genuine mental retardation, usually mild, often appears in conjunction with poverty, cultural deprivation, and familial deterioration (President's Committee on Mental Retardation, 1976). With her massive problems of population explosion, poverty, and illiteracy, India is likely to have much higher prevalence of mild retardation than in the Western countries. But because of social acceptance, the mildly retarded population in India is absorbed in the mainstream of national life. It is not, however, denying the fact that the problems of learning and social adaptation associated with mild retardation do not exist in India, or the mildly retarded population does not require any

attention. The existing social and economic problems, which are of immense proportions, will be much worse confounded, if this population is labeled as retarded without rendering any supportive service. Such labeling will have highly negative effect, and is, therefore, unwarranted.

The problem which requires immediate attention is that of "severe" retardation. Under this rubric, retardation at the moderate, severe and profound levels, as defined by AAMD (Grossman, 1973), will be considered for the present study. According to the President's Committee on Mental Retardation (1975), the prevalence rate for this population in the U.S. is .03 percent. One or more of the following handicapping conditions may be associated with severe retardation: ambulation, gross and fine motor control, speech, hearing, vision, seizures (epilepsy, convulsions), behavior and emotional disorders, and toilet training.

The research design will be adapted on the model of the social system epidemiology used in Riverside, California (Mercer, 1973). Three types of social systems to be contacted are: clinical organizations, nonclinical organizations, and neighbors, i.e., respondents in a household survey. As the laymen in Chandannagar are not much familiar with the term mental retardation or its implications, they will require some guidelines on the behavioral characteristics of moderate, severe, and profound levels of retardation at different age ranges. The illustrations of adaptive behavior functioning, prepared by AAMD (Grossman, 1973), will be used as a model to develop such guidelines keeping in mind the cultural disparity between India and the U.S. The staff to be involved in the survey will undergo intensive training for a couple of weeks so that they can also make judgment on classification of the levels of retardation by actually observing, if feasible, the behaviors of the individuals concerned at the time of household visitation. Although the project study is confined to

adolescents and adults (age 12 and above), the Chandannagar epidemiology will cover all age groups including those below age 12. This will be done to have an overall estimate of severe mental retardation.

Chandannagar municipal area has been selected as the geographic area for the project study, primarily because its population provides a representative sample for the State of West Bengal. The town proper is thickly populated, with its outskirts of rural areas. It is only 26 miles off from Calcutta, the State capital, and is connected by electric trains running every half an hour. It is thus in a position to receive professional assistance from institutions of higher education and other facilities located at Calcutta.

Development of Instruments

The two-dimensional definition of mental retardation, as enunciated by AAMD, is based on performance on standard measures of intelligence and assessment of adaptive behavior. The next step in the project operation is to develop instruments for this purpose. One performance scale for measuring levels of intellectual functioning will be constructed, with a standardization sample drawn from the Chandannagar area. A stratified random sampling plan will be adopted, after analysis of the latest census report which might be available from the local municipality. Norms will be developed for different age groups ranging from 12 to 59, if feasible. Performance sections of the Wechsler Intelligence Scales (WISC and WAIS), Revised Beta Examination and Raven Progressive Matrices will be especially reviewed for this purpose.

The behavior performance scale will be developed, after a thorough review of the AAMD Adaptive Behavior Scale, Cain-Levine Social Competency Scale, and Balthazar Scales of Adaptive Behavior. The normative sample in this case will be drawn from the severely retarded adolescents and adults, identified by the epidemiological study.

The TMR Performance Profile will be especially used to prepare profiles of individual subjects for evaluative purposes.

Programming

As mentioned earlier, the project is purported to establish a community-based residential facility for severely retarded adolescents and adults, with an adjunct day program to provide non-residential services and support to such other retarded persons as would continue to live at home. The training programs will be designed to prepare the individuals to better cope with the community and to provide a relief aspect to parents. The composite model will operate on the principles of normalization.

DiMichael (1971) has proposed to rehabilitation workers a classification guide for mental retardates, based on their overall vocational prospects: (1) Directly placeable group (from school to job), (2) Deferred placeable group (postschool preparation to job), (3) Sheltered employable group, and (4) Self-care (nonself-supporting group). Taking into account the serious unemployment situation in India and the severe level of retardation of the project subjects, the first two categories do not apply in this case. The last two categories actually constitute the underlying standards of normalization in the present context. The sheltered employable group should be capable of partial self-support in the carefully supervised environment of a sheltered workshop. The nonself-supporting group will include persons who may partially care for themselves in the home and may be able to participate in a "social therapy center" but who are not capable of engaging in productive employment even in a sheltered workshop. This latter group should be rehabilitated for independent living, which is of utmost import in the normalization process in India.

Based on the findings of the epidemiological study, 30 subjects will be initially selected for participation in the project. These individuals should be

ambulatory and toilet trained. Fifteen subjects, who are most severely retarded, will be placed in the residential program; the other fifteen, who are less severely retarded, will be included in the day training program while they live at home. Before recruitment, these subjects will be medically examined, and psychometrically tested to the extent possible. In all cases, consent of the parents or guardians will be obtained for placement in the relative programs.

After watching the results for six months, the number of subjects will be raised to forty. The additional 10 subjects will be equally divided between the two programs. Based on the progress of their performance, the subjects from the residential program will graduate to the day program. The subjects from the day program will be encouraged to leave the program, if and when they can find self-employment, homemaking, farm or family work (including work for which payment is in kind rather than in cash), sheltered employment, or homebound employment. A followup service will be provided to all the day program subjects throughout the project period.

Some of the community services, training methods and techniques, and supportive programs, mentioned in the section on Objectives, are briefly explained below.

1) Developmental model - providing attention to specific problems and needs of individual subjects until they can be corrected or met. Thereafter, the individual progresses to an improved level of independent functioning.

2) Behavior modification technique - to be applied to control undesirable behavior in subjects, make them more cooperative, and teach them self-help, language, motor coordination, and social recreational skills.

3) Group milieu approach - small groups, each composed of 8-12 persons with their own instructor, to be set up to develop group contacts during the day. Each such group should form into a work group, and continue at work outside the institution on a long-term basis (Chigier, 1973).

4) Activity Center - to serve more severely handicapped individuals who are not yet ready for sheltered work. Training in basic activities (grooming, personal adjustment, travelling) and social programs are provided with the hope that individuals will become less dependent on others.

5) Sheltered Workshop - special workshops which offer market-based employment opportunities for the handicapped in protected work stations provide a large proportion of the rehabilitation training for mentally retarded individuals. Generally, employees in workshops perform piece-work under contract with local industries.

6) Parent education program - to provide practical assistance and counseling to mothers in the everyday problems of rearing a mentally retarded child and in coping with the diverse problems presented by retarded adolescents and adults.

7) Volunteer program - effectively using volunteers as an innovative resource.

8) Advocacy program - to be developed to evolve a system accountable to retarded people and their parents, and to insure a quality of life compatible to the needs of all people. The program will be designed to advocate especially for the profoundly and severely, multiply handicapped.

Followup Program

Followup services of the project subjects, who return home during the pendency of the project, will be provided by paraprofessionals especially trained for the purpose. They will try to meet the needs of the subjects, and bring to the notice of the proper echelon any crisis situation that may arise and require immediate intervention.

Hopefully, Vidyarthi Bhawan will continue the program on the expiration of the project period, with the subsidies it may receive from the State and Central Governments. A special followup study on the project subjects should be undertaken at that stage, to evaluate the overall effectiveness of the program.

Program Evaluation

As mentioned elsewhere, behavior modification techniques will be the primary tool to change specified behaviors in the subjects. Single subject data on observed change of behaviors from the baseline state will be evaluated, say,

at an interval of six months to estimate the effectiveness of the intervention program. Such data will be generated from the adaptive behavior scale measures.

In addition, each individual subject's performance level in a wide variety of daily living activities will be identified periodically, with the aid of TMR Performance Profile.

Lastly, consumer evaluation of services by the parents or advocates of the subjects will be conducted periodically. An individualized written rehabilitation plan, to be developed in collaboration with the parents or advocates at the time of the subject's admission to the program, will be used for the purpose.

Concluding Remarks

At the 1976 APGA Convention at Chicago, Ramsey Clark, former U.S. attorney general, and one of the main speakers, quoted Earl Warren, former U.S. Supreme Court Chief Justice, stating, "There is an imperative need to create a political conception of passion." Clark further said: "Citizens want to be involved because they want to have an affect on the quality of life. Social service must become the dominant occupation." The political conception of passion and the spirit of social service surely apply to the present day world which has become increasingly interdependent. These are the basic philosophies which have prompted the philanthropic institution of Prabartak Samgha to develop the R&D project in order to serve a unique humanitarian need. The project will demonstrate that the pitiable plight of the severely retarded, who are forced to live a subhuman life even in the family environment, can be ameliorated to the level of their potential through concerted efforts of their fellow brethren. It will also present a model of parent education so that parents may become cooperative participants in the programming of their retarded wards to provide a continuity in extramural services. The project will further exhibit the possibilities of eliminating the problems of post-institutional adjustment, by providing comprehensive community services in a complex of human service program. This innovative approach in habilitation programming may serve as a model for other Indian states, and even for some other countries.

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